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ABSTRACT

Seventy-five families of children with special needs were interviewed after one year's experience with early intervention services and 69 of these families were then re-interviewed a year later after two years of such services. Five themes were identified in the families' views of "what works well." These were: (1) consistency of staff, (2) home visits, (3) programs providing financial support, (4) professionals who support parents and respond to their needs, and (5) professionals who show parents how developmental play stimulates the child's development. Suggestions from parents for other parents and service providers stressed the following: parents need to fight for services and advocate for their child; parents should get involved in an early intervention program as soon as possible; parents want information; parents value support from and connection with other parents; and parents need to take care of themselves emotionally. Other findings indicated that parents experience a somewhat fragmented service system, which requires that they learn different rules for dealing with different subsystems (e.g., social services, education). (Contains 10 references.) (DB)

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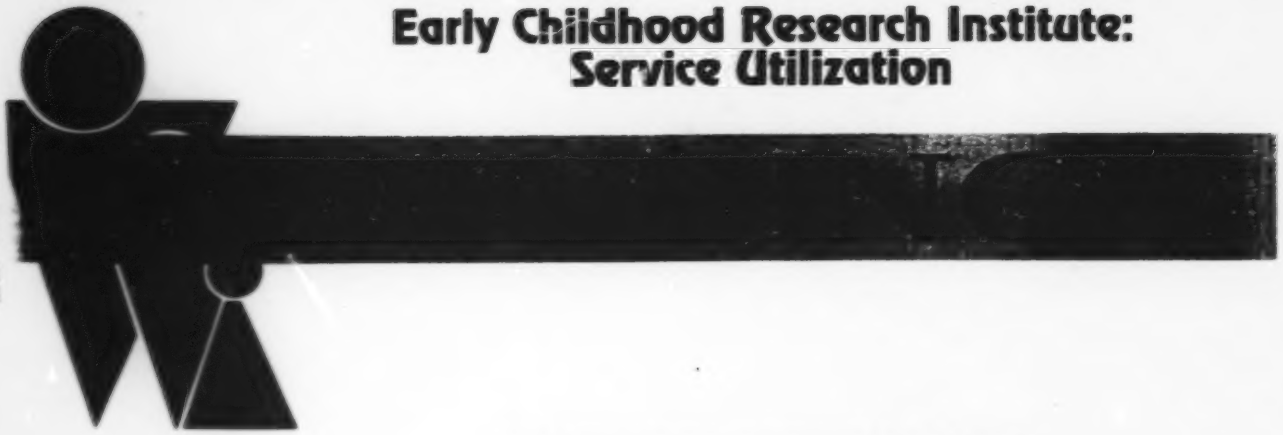

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FAMILIES' REFLECTIONS ON THEIR EXPERIENCES WITH EARLY INTERVENTION SERVICES *

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One of the benefits parents derive from meeting other parents is sharing the wisdom accumulated through experiences in early intervention. The importance of families' opinions and contemplations as consumers is increasingly recognized, as the increasing use of parents in personnel preparation activities and legislative development shows. In trying to understand how different interpersonal and systemic factors influence service use patterns, therefore, it seemed obvious we should take advantage of consumers' observations.

As part of the work of Early Childhood Research Institute: Service Utilization, we interviewed 75 families who have children with special needs about their experiences with early intervention services. One year later, we conducted a second interview with 69 of the families, asking them about their 2 years of early intervention services. Families' responses to these questions provide valuable information to other families and to providers within the service system about the factors that help families gain access to and use early intervention services. Parents were asked the following questions:

1. In thinking about your whole experience with early intervention (infant-toddler or preschool services or both), what are the changes you would make that would have made your experience better?

2. What are the things about early intervention that work really well?

3. What do you wish someone had told you about these kinds of services when you first became involved with them?

4. What advice or guidance would you give to parents who are entering this system for the first time?

The responses to these questions were analyzed using an iterative qualitative-analysis process (Miles & Huberman, 1994). All responses to each question were grouped, and emerging categories were identified. We then sorted categories until themes across each reflection question had been identified. Themes were then compared across questions to check for similarities.

The second question (What works well?) yielded five distinct themes. Questions 1, 3, and 4 yielded similar categories that we consolidated into five themes. Themes and statements from families that most clearly illustrate the themes are presented below. Names of family members and service providers used in examples

*NOTE: In this publication, we use the term *early intervention* generically, to refer to services for infants, toddlers, and preschoolers. When we need to distinguish between *infant-toddler services* and *preschool services*, we use those terms.

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and quotations have been changed to protect their confidentiality.

THEMES FROM QUESTION 2: WHAT WORKS WELL?

Consistency of Staff

Working consistently with the same service provider(s) is a positive thing for families. Families who had had 2 years or more of experience with the same service provider said that this consistency in staff helps them to develop strong, trusting relationships with their service provider that continue to grow and develop over time. These service providers and the services they offer are seen as a constant in the family's life — a constant upon which the family depends.

Home Visits

Parents see home visits as positive because they add an element of convenience to their hectic lives and occur in a place familiar for the child and parents (see Bailey & Simeonsson, 1988). "It's nice that they come to the house," said one mother. "Working in the home helps a lot and is more comfortable for the child." Some parents were not initially happy with the idea of home visits but grew to like them because of their convenience. One mother said, "Even though I didn't like people coming into my home at first because we're private people, it is more convenient. We've worked with the same people and it's been really good." Another mother wanted to have intervention-planning meetings in her home specifically because it provided her with the opportunity to reciprocate kindness toward her service providers. This mother made these meetings like a party, with entertainment and refreshments.

Programs Providing Financial Support

Parents appreciated the financial programs that provide assistance to children and families like Medicaid; Children with Special Health Care Needs, also known as the Handicapped Children's Program (HCP); Women, Infants, and Children (WIC); Supplemental Security Income (SSI); and other such financial programs (see Clifford, Bernier, & Harbin, 1993). These programs help families meet medical, nutritional, daycare, and other basic needs. When a family is eligible for and begins to receive the financial service regularly, parents said this support helped to alleviate significant stress in their lives. "Monies through HCP were helpful," said a parent. "HCP was difficult to navigate but worth it." "WIC is a good program," said another. Unfortunately, a large subset of families in our study also described many difficulties in gaining access to and navigating the bureaucracy surrounding these financial services.

Professionals Who Support Parents and Respond to Their Needs

Parents value service providers who they feel support them both emotionally and through responding to their expressed needs (cf. McWilliam et al., 1995). Parents said that a service provider with whom they have developed a close relationship provides them with reassurance about their parenting and their child's development. One mother said service providers are "beneficial to families by providing support, caring, and reassurance around development."

"My child may or may not have developed to this level without services, but the support to parents from providers is very important," said another. Sometimes, the relationship between a provider and a parent feels like a *mentoring relationship*, where the mother feels nurtured and supported by the service provider for a period, as the mother grows and evolves in her role. This type of relationship with their service provider was described by many mothers as a highly supportive and significant relationship in their lives (see Dunst, Trivette, & LaPointe, 1994).

Through Their Work, Professionals Show Parents How Developmental Play Stimulates the Child's Emerging Development

"What works is parents and workers one on one, showing parents how to do things with their child's development." Many parents described as valuable the process of the parent's working with the service provider on specific activities to stimulate their child's development (cf. McBride & Peterson, 1994). "I have good instincts about how to work with my child," a parent said. "But the therapist helped to provide education around my child's development that gave me a richer, more global picture of my child's development."

Another parent said, "They have really worked to teach me how to work with my child."

THEMES FROM QUESTIONS 1, 3 & 4: WHAT DO YOU WISH SOMEONE HAD TOLD YOU? WHAT CHANGES WOULD YOU MAKE? WHAT ADVICE WOULD YOU GIVE?

Parents Need to Fight for Services and Advocate for Their Child

"Keep fighting and don't ever give up." This expresses the feelings of many parents who have learned through their experience that "you have to fight for your child." Parents described needing to "set your mind on what you want and make them give it to you," and expressed that "they (systems) make it so hard to do because you have to get angry and get them mad at you before they will give you what you need" (see McWilliam

et al., 1995). Some parents take on their role of advocate automatically and naturally. Other parents have to learn how to advocate and do so through a combination of learning from their own experience, learning from the experiences shared by other parents and learning through encouragement from their service provider. Some parents indicated that they were told by service providers and other parents that they would need to be advocates for their child. "The advice that we did receive was that there will sometimes be battles to get what your child needs," said a mother. "But you have to do that. You have to push for what you want. Even Linda (service provider) told us this and said that we have to be the advocates for Randy."

Understanding that parents have rights is the turning point for many parents such as the mother who said, "The best thing that happened to me was that I learned that I had rights as a parent, that I could call the shots and didn't have to accept whatever I was given." Along with this, parents learned to trust and value their parental instincts and have confidence in their decisions. "Believe in yourself that you are a good parent and that your instincts are good. Your instincts are important," said a parent.

"Trust your instincts and have confidence that you are making the best choices for your child," said another. Parents would advise others that sometimes services and programs do not work, and that sometimes professionals are not helpful, but that families must continue to advocate and find the best services for their child.

Get Involved In an Early Intervention Program As Soon As Possible

Overwhelmingly, families said that the first advice they would offer new families is to become involved right away in the services available through an early intervention (infant, toddler, or preschool) program. Many families said that they would introduce new families to specific service providers who had been helpful to them and offer information about services and supports of which they were unaware when they first entered the system. One parent noted that she would provide "a new family with the information about services that I have fought to obtain." Many of the parents described the challenges they faced in trying to navigate the system and advocate for their children. Their aid to new families would be to provide them with the information they gathered so that these new families would face a more easily navigable and user-friendly system (see Dinnebeil & Rule, 1994; Dinnebeil, Hale, & Rule, 1996).

Parents Want Information

Parents expressed needs for information in three areas: early intervention programs, financial assistance programs such as Medicaid and Social Security Insurance (SSI), and information that helps parents to understand and work with their child's condition (e.g., Down Syndrome) and development (cf. Gowen Christy, & Sparling, 1993). The information parents want about early intervention programs includes explanation of the services, what the programs offer, and what parents are entitled to as well as being directed to these programs earlier. "I wish I was more informed in general about what I should get," said a mother. "Every parent should be given a book about what their child is entitled to."

Another mother said, "I wish I had known about this program earlier; both my children would have been in it."

Parents describe needing to learn how to navigate other service systems and they rely on the early intervention program to help them learn this information (see Sontag & Schacht, 1993). "I wish someone would have better explained to me how to negotiate Medicaid, WIC, and other financial services," one mother said plaintively.

"Parents need more information about SSI and Medicaid" said another. Many parents discovered that the key to obtaining solid information lay in the identification of one knowledgeable contact person. "Give me a good contact person," said a parent, "and I'll do the rest."

Parents also want more information about their child's development and how the activities of the intervention are related to improving the child's development. "It would have been helpful to have had more teaching from professionals around my child's development and how the activities that they did with my child stimulated her development."

Parents Value Support From and Connection With Other Parents

Many parents wanted more support from other parents whose children had similar developmental and health issues and parents who had similar experiences with their child. "I would have liked connections with mothers who had been through the same thing with their child," said one mother.

"I wish I could have talked with someone in my situation who could have helped with what I was going through," said another. "This is especially important for single mothers where there is no supportive husband." One mother said that she would tell new parents to "call me anytime, even at 4:00 in the morning and I'd mean it." Families said that talking with other families who are experiencing similar stresses and are in similar situations

gave them hope and strength to get through difficult times.

Take Care of Yourself Emotionally

Many parents would tell other families to love themselves and their children unconditionally. This advice includes parents' taking the time to do things for themselves so that they will have the energy to better help their child. One parent advised that families should treat their child "not as a child with special needs, but as they would any other child."

"Relax and love every minute of their childhood," was one mother's advice to other families.

Summary

The feedback families provide about their experiences with infant, toddler, and preschool services helps us to see how to improve the existing service system. Unfortunately, families describe a somewhat fragmented service system that requires they learn different sets of rules for dealing with different subsystems (e.g., social services, education). Legislation needs to be directed toward unifying these subsystems into a unified system of early intervention.

Service providers who provide emotional, educational, and informational support to families provide a vital link between the family and the service system. This person and the family's comfort in their relationship with him or her can help the family to navigate the sometimes choppy waters of service use. Personnel preparation efforts need to be aimed, not only at educational support, but at emotional and informational support to be provided in the form each individual family requires.

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